

# HEALTH INEQUALITIES: TIME TO TALK.

Reopening the debate  
on fairer cancer care

**MACMILLAN**  
CANCER SUPPORT  
RIGHT THERE WITH YOU



**My finances are very affected because I can't work but I have to spend more money because I have to go to the hospital most of the time for appointments etc ... I have to pay hospital car parking all the time and also for fuel, but am still going to my treatment.**

Sandra, 43, diagnosed with breast cancer

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Case studies used in this report all provided informed consent to Macmillan and are used with permission. We identified each as having difficulties with income or related aspects associated with 'multiple deprivation'. To protect anonymity, names have been changed. Based on the preceding evidence, each provides the experience of a socio-economically deprived person living with cancer.

## Executive summary **The case for action**

This year, more than 300,000 people in England will receive the life changing diagnosis of cancer.<sup>1</sup> And the number of people living with cancer is predicted to rise by 3.2% each year.<sup>2</sup> But for too many people, who they are or where they come from will determine what happens next. Socio-economically deprived and low-income groups too often face the prospect of poorer access to the care they need, at the times they need it most.

Their chances of receiving vital support could be further limited by ‘social determinants’ that continue to impact their health and wellbeing after their diagnosis – including their emotional needs, practical needs, access to social care and community setting. These factors can determine which individuals have the opportunity to have the highest possible quality of life, even after a cancer diagnosis.

### Our vision

Macmillan believes that even where people are living longer with cancer, this must also mean living life as fully as possible.

This report outlines how, together, we can make that vision a reality. It follows the cancer pathway, highlighting the systematic injustices socio-economically deprived people face at every turn. It provides new evidence and insight to inform what we need to do in England, following the NHS Long Term Plan, to ensure everyone with cancer has an equal opportunity to live as well as they can.

#### Early diagnosis

Compared to the highest income groups, people in the most income deprived areas in England are 20% more likely to have their cancer diagnosed at a late stage.<sup>3</sup>

**People in the most socio-economically deprived areas in England are 20% more likely to have their cancer diagnosed at a late stage than people in the least deprived areas.**

#### At the point of diagnosis

Socio-economically deprived people living with cancer have consistently worse experiences at the point of diagnosis, including:

- test results not explained in a way they can fully understand
- not having all the information needed about a diagnosis
- less frequently receiving written information about the type of cancer they had in a format or language right for them.<sup>4</sup>

#### Personalised care planning

Macmillan believes that the system should place a person’s holistic needs at the heart of treatment and care. Barriers to high-quality, personalised care for socio-economically deprived people include:

- poorer conversations with healthcare professionals
- less involvement in decisions about care and treatment
- less support after treatment from community and social providers.<sup>5</sup>

#### Access to treatment

There is variation in access to treatment. Compared to people in the least socio-economically deprived areas of England, people living with cancer in the most socio-economically deprived areas had:

- less surgery (40%, as opposed to 48% in the least deprived areas)<sup>6</sup>
- half the referrals to early stage clinical trials.

**People living with cancer in the most socio-economically deprived areas receive only half the number of referrals to early stage clinical trials given to those in the least deprived areas.**

#### **NHS workforce**

A fully funded, trained and sustainable NHS workforce is critical for meeting everyone's needs. But there is also a specific need for more consistently high-quality conversations between NHS staff and the most deprived people, who report they are:

- more likely to need support to understand information about their health and care, but less likely to receive it at an adequate level
- less often treated with respect
- less likely to feel acknowledged and involved by their care team.<sup>7</sup>

#### **Emotional and psychological support**

A cancer diagnosis comes with understandable anxiety and fear. These emotions can strike at any time in the cancer pathway. Indeed, 45% of people living with cancer have unmet emotional needs.<sup>8</sup> But these needs are felt more often and typically, more severely, by the most deprived groups. New Macmillan analysis, presented for the first time in this report, shows that in the UK people living with cancer and on the lowest income are almost twice as likely to mention a need for more emotional support than those with larger household incomes.

**People with the lowest incomes are almost twice as likely to report a want for more emotional support than people on higher incomes.**

#### **Practical support and social care**

Around two in three people living with cancer have practical support or social care needs (64%).<sup>9</sup> These can determine their opportunity to live well even after the shock of a cancer diagnosis.

New Macmillan evidence, presented in this report for the first time, shows that in the UK:

- inside the home, people on a low income are twice as likely as people on a high income to say that they would like more practical support (38% vs 19%)
- outside the home, people on a low income are almost three times as likely as people on a high income to say they would like more practical support (34% vs 13%).

**People with the lowest incomes are twice as likely to need more practical support inside the home, and three times more likely to need more practical support outside the home than people on a high income.**

#### **Integrating care in the community**

As Macmillan's experience of the Improving the Cancer Journey (ICJ) programme has shown, integration can improve care for everyone, particularly the most socio-economically deprived people in our society. Service users are predominantly the most socio-economically deprived (61%); have significant non-clinical needs (with finances, housing, practical tasks and getting around); and multiple conditions (54% had at least one other long-term condition). On average for users of the ICJ, self-reported 'severity of concern' is halved, and quality of life increases.<sup>10</sup>

### At the end of life

Macmillan evidence shows that people from the most income deprived areas face almost **five** emergency admissions to hospital on average in their last year of life (compared to around **four** in the least deprived areas).<sup>11</sup> They are also more likely to die in hospital.

There is likely to be a significant cost to the care system. Emergency admissions in the last year of life cost the NHS **£2.5 billion** every year in England alone<sup>12</sup>. Indeed, emergency admissions overall represent a significant portion of **health expenditure since 2011/2012**.<sup>13</sup>

People living with cancer in the most socio-economically deprived areas faced almost **25% more emergency admissions (5) in their last year of life** compared to people from the least deprived areas (4).

## Opportunities for real change

Ten years on from the Marmot Review as well as what has been called the ‘English Inequality Strategy’ [1997-2010],<sup>14,15</sup> we need a compelling vision to reduce health inequalities fit for the next decade. While some responsibility for addressing inequalities will necessarily need to be devolved and addressed at a local or neighbourhood level, national governments across the UK must lead by example and take responsibility for delivery.

We believe a national approach to tackling health inequalities needs to build on the following three foundations:

1. **A clear vision for tackling inequalities both locally and nationally, to ensure that measurable plans and objectives push in the same direction.** This should look to facilitate a whole-systems approach to tackling inequalities– with action across public services. This would mean the inequalities people face before and after a cancer diagnosis can be systematically addressed – and not just left in a ‘health service silo’.
2. **A clear account of the exact resources, evidence and support local providers will need from national governments to deliver on inequalities** – and a plan to provide the full support they need.
3. **A commitment to targeted action where inequalities are most in need of attention – that is, to ensure that new health policies and interventions consider from the outset how they will benefit the most commonly excluded groups.** Action should see new services and interventions evaluated in terms of how they improve outcomes for groups experiencing the worst outcomes today.

Ultimately, the most effective way forward would be for Government to take cross-cutting action to tackle inequalities, driven by (but not limited to) health and care organisations. Health inequalities need national attention, but they are experienced in people’s neighbourhoods and communities. So action must be taken at both a regional and local level – with a clear onus remaining on national bodies and Government to provide continued support, resource, evidence and vision to drive us towards real change.

# KEY FACTS

People living with cancer in the most socio-economically deprived areas:

- **are 20% more likely to have their cancer diagnosed at a late stage**
- **receive only half the number of referrals to early stage clinical trials**
- **face almost 25% more emergency admissions in the last year of life**

compared to people in the least deprived areas.



People with the lowest incomes:

- **are almost twice as likely to report a need for more emotional support**
- **are twice as likely to want more practical support inside the home**
- **are three times more likely to need practical support outside the home**

than people with a higher income.

## **A much needed debate**

This report is designed as a prompt for debate, following the Long-Term Plan for England released earlier this year by NHS England. It outlines the problems, and some early thinking around possible solutions policy-makers need to address. Our starting position is that health inequalities are unacceptable, but— despite good examples of local action— have been neglected for too long as a national policy priority. This report is not intended to provide answers on how to reduce all the inequalities people living with cancer experience, but instead, provide a foundation for discussion and collaboration between local, national and third sector partners over the coming years.

## Introduction

In 2015, 2.5 million people were living with cancer in the UK – which is predicted to rise to 4 million by 2030.<sup>17</sup> In 2016, in England, 303,000 people received the life changing diagnosis of cancer.<sup>18</sup> If you are diagnosed with cancer, your income or socio-economic status certainly shouldn't determine your outcomes, your care or your quality of life. However, in 2019, it remains a factor that determines outcomes for people living with cancer.

### The cost of inequality

People from the most socio-economically deprived areas in England can expect a decade of lower life expectancy and up to almost two decades less in reasonable general health than people in the least deprived areas.<sup>19,20</sup> In England alone, the cost of health inequality is at least £20 billion annually.<sup>21</sup> This makes the health inequalities agenda not just one of championing social justice, but one of economic good sense as well.

### Defining an approach to health inequalities

However, only focusing on a reduction in inequalities in life expectancy may prove too blunt an approach. For example, and though there is much work still to do to reduce the inequality gap,<sup>22</sup> overall cancer survival rates are improving.<sup>23</sup> Indeed, living ten or more years after a cancer diagnosis has become far more common, with the ten-year survival rate for all cancers passing 50% in 2010 for people living in England and Wales.<sup>24</sup> People on average are twice as likely to survive at least ten years after being diagnosed with cancer than they were at the start of the 1970s.<sup>25</sup> In that context, Macmillan believe living longer with cancer needs to mean living well. This must be reflected in England's vision and approach to tackling health inequalities. That is, we must also address any impact a low income and socio-economic deprivation has on the opportunities or capacity of people with cancer to live as fully and as independently as they can.

The realities of cancer make a 'whole-system' approach to health inequality crucial. This needs to be a national approach, confronting:

- a) the wider social determinants of health, such as income poverty
- b) pre-diagnosis lifestyle behaviours and 'risk factors'. For instance, smoking, which accounts for over half of the difference in risk of premature death between social classes<sup>26</sup> and there are well-established interventions to reduce risk.<sup>27, 28, 29</sup>

However, 6 in 10 cancers are not attributable to known risk factors,<sup>30</sup> meaning many people will continue to rely on primary, acute and community care and support for cancer at some point in their life. **Therefore, any approach on health inequalities should also prioritise inequalities that endure or worsen after the point of diagnosis.**

#### Defining deprivation

'Socio-economic deprivation' refers to the Index of Multiple Deprivation (IMD) which considers income, employment, education, health, crime, barriers to housing and services, and living environment.<sup>16</sup> For the purposes of this report, we bring together the literature on how socio-economic deprivation, and particularly income inequality, impact the experiences and outcomes of people living with cancer.

We're actively looking to better understand how health inequalities associated with low income and socio-economic deprivation can be addressed after someone receives a cancer diagnosis. We specifically focus on England, in the context of NHS England's Long-Term Plan, released in January 2019. This is an area with relatively limited policy thinking, but one which needs urgent attention. This report provides emerging insights into the inequalities socio-economically deprived people living with cancer experience and how that affects their health outcomes and wider wellbeing.

## Inequalities throughout the cancer pathway

The report follows a typical cancer pathway, from the point of diagnosis onwards. What the emerging evidence demonstrates is how – throughout that pathway – inequalities systematically exclude some people from the level of care, and the health outcomes we know NHS and care providers can deliver at their best.

The picture we paint shows how health services are designed and how we distribute health resources – classic questions of access to services, treatments and the health and care workforce. We call this 'health system inequality': a factor estimated to explain around 15-43% of inequalities in life expectancy depending on the estimate and the country studied.<sup>31</sup> This makes the health and care system itself at least one of the largest single determinants of health inequality.

But the story on inequalities that unfolds in this report is also driven by social and economic determinants that persist after the point of diagnosis and can worsen people's health and wellbeing when they are already living with cancer. Put another way, these are the opportunities a person has for a good quality of life after diagnosis. We define these factors as the social, practical, relational and psychological factors – all of which shape your experience of living with cancer.

## Approaching Inequality

We believe a national approach to tackling health inequalities should be built on three core principles:

1. Tackling inequality more widely in society.
2. Public health interventions to reduce risk-factors of ill health.
3. Work to reduce inequality after the diagnosis of a condition like cancer.

This report focuses on the third of these – inequalities experienced when someone is already living with cancer – as an area we believe is under-developed and needs urgent policy attention.

## Opportunities for action

The coming year provides immediate opportunities to tackle health inequalities for people living with cancer, both at a national and a more local level.

By next year, 2020, a whole decade will have passed without a strategic, national-level approach to tackling health inequalities. In England, it will be ten years since what is often called the 'English Inequality Strategy' [1997-2010]<sup>32, 33</sup> – an approach shown to have had long-term impact on levels of inequality<sup>34</sup>, and which combined ambitious targets with local action and spearhead areas. The period also saw the publication of Fair Society, Healthy Lives (the Marmot Review). While this was never fully implemented, it showed the extent of health inequality – and made the case for making it a top priority for action.<sup>35</sup>

Looking back, these years have seen a disappointing focus on piecemeal action by national government, with the good practice we have seen mainly driven by local health and care partners. This makes it ever more important for us to seize this opportunity to take direct action on the causes of inequality, on public health, and also, critically, on the known inequalities faced by people living with cancer.

Indeed, in the next year there are excellent opportunities to more systematically prioritise action on health inequalities. More funding for services in our most socio-economically deprived areas was a welcome part of the NHS Long-Term Plan for England. Measurable local objectives for the next five and ten years – expected in Sustainability and Transformation and Integrated Care System plans by autumn – offer local NHS and care partners a real opportunity to use funding to drive improvements across the cancer pathway.

Work to tackle health inequalities has already been a feature of many local NHS plans and while Macmillan supports this, now is the time to broaden horizons and ensure inequalities are addressed both in terms of reducing cancer incidence, but also after diagnosis; when cancer is incurable and right through to end of life.

### Three crucial priorities

If we want to ensure sustained, measurable progress and reverse the trend of widening health inequalities, we need even greater ambition headed into the next decade. Macmillan identify three core components not currently present in the government's approach to health inequalities, but that are necessary components of a compelling vision on this agenda fit for the 2020s:

1. A clear vision for tackling inequalities both locally and nationally, to ensure that measurable plans and objectives push in the same direction. This should look to facilitate a whole-systems approach to tackling inequalities– with action across public services. This would mean the inequalities people face before and after a cancer diagnosis can be systematically addressed – and not just in a 'health service silo'.
2. A clear account of the exact resources, evidence and support local providers will need from national governments to deliver on inequalities – and a plan to provide the full support they need.
3. A commitment to targeted action where inequalities are most in need of attention – that is, to ensure that new health policies and interventions consider from the outset how they will benefit the most commonly excluded groups. Action should see new services and interventions evaluated in terms of how they improve outcomes for groups experiencing the worst outcomes today.

**Macmillan's aim is to restart the debate we need to have on this vital issue – and, together, build a consensus on the best way forward.**

## Early diagnosis

People from the most income deprived quintiles\* are less likely to receive an early diagnosis when they have cancer. A 2012 study by Lyratzopoulos et al. – looking at 10 of the most common cancers in England – calculated a 20% increased risk of later diagnosis (stage III or IV). The risk was over double for some cancers, such as melanoma.<sup>36</sup>

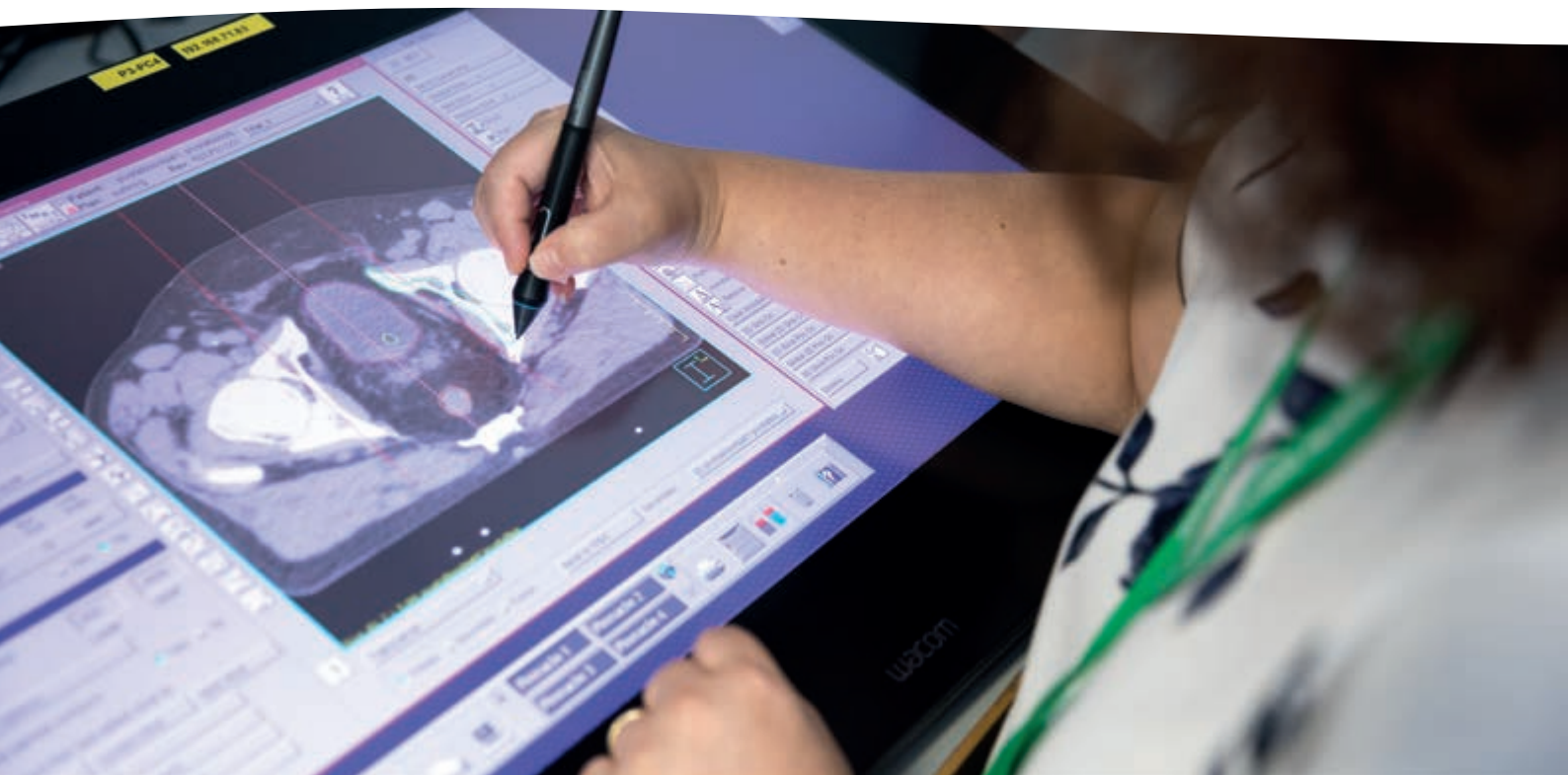
There are several explanations for variation in stage of diagnosis, including but not limited to:

- Large inequalities in the uptake of cancer screening services in socio-economically deprived areas, even though screening saves lives. This has been shown in relation to bowel,<sup>37, 38</sup> breast<sup>39</sup> and cervical screening programmes.<sup>40</sup>
- Differences in health literacy, awareness of symptoms and attitudes about cancer. These have also been linked to healthier behaviours and the stage of diagnosis.<sup>41</sup>
- Reduced ability and opportunity to seek support. Exploratory studies have indicated that the more socio-economically deprived a person, the harder it is for them to seek help – an understandable reality of having a longer list of essentials they need to manage, whether financial, psychological or relational.<sup>42</sup>

Delays in diagnosis can lead to later stage cancer diagnosis, more complicated care and treatment, and greater reliance on emergency services. This translates to worse outcomes, quality of life and experience of care – as well as increases in potentially avoidable health expenditure.

Earlier diagnosis for all represents a necessary component to any plan for tackling health inequalities. It was welcome to see a range of commitments to earlier diagnosis in the NHS Long Term Plan for England. However, it's also important to remember that sustained progress diagnosing cancers earlier is unlikely to be enough, by itself, as a solution to tackling inequality. Indeed, evidence from studies of breast cancer patients shows clearly that early diagnosis only partially accounts for inequalities in survival outcomes.<sup>43, 44</sup> It's clear we need to look across the whole cancer pathway.

\* Defined as places with higher levels of multiple deprivation, as per the English Indices of Multiple Deprivation, unless otherwise stated



## The point of diagnosis

Inequalities do not stop when a cancer is diagnosed. From the point of diagnosis onwards, there are many that need systematic attention – locally and nationally.

A cancer diagnosis is life changing. Beyond the impact on someone's health, it comes with emotional, practical and financial consequences. It's a time where people often have complex, multiple needs, and it's vital people get the right support here. So it is incredibly worrying that deprivation is linked to both diagnosis via a health emergency, and emergency admissions to hospital in the months immediately after diagnosis.

### Emergency admissions and mortality

In a study of national hospital records looking at all colon cancer patients diagnosed between 2011 and 2013, the most income deprived patients with tumour stage I, II and III also had more hospital emergency admissions in the months following their diagnosis.<sup>45</sup> Worryingly, an emergency admission is also directly linked to death in the first 90 days of diagnosis. This may indicate poor care planning and a lack of support to enable people to self-manage their care. It may also be due to uncoordinated care for some of the most deprived patients.

What really stands out here is that the link between deprivation, emergency admission and death after diagnosis was present whether the colon cancer diagnosis was early stage (stage I or II) or later stage (III or IV). This suggests that a solution does not lie only with earlier diagnosis, but rather a: "focus on deprived groups and aim at integrating social and health care. For instance, patients that exhibit recurrent HEAs [Hospital Emergency Admissions] in a short period of time reflect either clinical complications, sub-optimal health care administration, premature discharge or a lack of social support. Disentangling the causes for recurrent HEAs requires a case by case analysis and an efficient communication with the health professionals".<sup>46</sup>

### Time of diagnosis is also a time of need

It also suggests that the time of diagnosis itself should be considered as a time of need from an inequality perspective.

Indeed, results from Cancer Patient Experience Surveys also highlight the problems faced at diagnosis by people from the most deprived areas. These relate particularly to waiting times or communication with healthcare professionals. Statistically significant differences compared with the least deprived are highlighted overleaf (Table 1 overleaf).

The differences are all statistically significant, and though differences are not always substantial, they are almost always worse for the most deprived people living with cancer by 2–4%.

The trend is clearly and consistently worse experiences for people from the most income deprived areas – and scores around people's interactions with their healthcare professionals are particularly worrying. We discuss the need for improved communication across the cancer pathway later in this report [see the chapter on the health and care workforce]. Significant differences by socioeconomic status in cancer patient experience at point of diagnosis were not seen in Welsh or Northern Irish Cancer Patient Experience Surveys.

There are two exceptions. The first relates to people being told they could invite a family member. The second to those who felt positive about the way they were told they had cancer. These are likely a vindication of the work we know trusts have been doing on patient experience scores.

Level of deprivation	Most deprived	Least deprived
Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer? (% went more than twice)	<b>73%</b>	<b>78%</b>
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor? (% Positive)	<b>83%</b>	<b>85%</b>
Beforehand, did you have all the information you needed about your test? (% Yes, definitely)	<b>93%</b>	<b>95%</b>
Were the results of the test explained in a way you could understand? (% Yes, definitely)	<b>77%</b>	<b>81%</b>
When you were first told that you had cancer, had you been told you could bring a family member or friend with you? (% Yes)	<b>80%</b>	<b>76%</b>
How do you feel about the way you were told you had cancer? (% positive)	<b>86%</b>	<b>84%</b>
Did you understand the explanation of what was wrong with you? (% Yes, definitely)	<b>72%</b>	<b>74%</b>
When you were told you had cancer, were you given written information about the type of cancer you had (% Yes)	<b>72%</b>	<b>74%</b>

Table 1: Results from the National Cancer Patient Experience Survey (NCPES) 2017 in England. Scores provided for Indices of Multiple Deprivation for quintiles 1 (most deprived) and 5 (least deprived). Univariate analysis\*, only significant differences shown.<sup>47</sup>

\* Other demographic factors were not included for analysis



## Impacted by health inequality

### Mary, 27, Lancashire

Mary was struggling financially and very worried about her health. Her concerns were misdiagnosed as mental health issues and she was sent away with antidepressants. She had to visit her GP multiple times, but eventually was admitted via A&E. By the time she was diagnosed with cancer, it was almost too late.

I knew there was something wrong long before I was given a cancer diagnosis. I was finding it impossible to sleep for 12 months. My GP told me it was nothing more than anxiety and depression and gave me antidepressants. Eventually I admitted myself to A&E. Two weeks later I was told that I had three tumours in my neck – which my GP could have felt – and that had I left this for another few weeks, it might have been too late ...

### Swati, 61, South Yorkshire

Swati is a woman living on a low-income. Her sister had died from breast cancer in 1989, so she was alert to the possibility she too had cancer when she started experiencing symptoms. However, her GP dismissed her concerns based on her age. At the time, she was also a carer for her husband, who suffers from multiple long-term conditions.

When I first had symptoms I really felt that something wasn't right, but clearly the GP did not think so. She asked my age. When I told her I was 54, she said 'oh well, then it must be the menopause'. A while after that I was told that I was due a routine mammogram. When I went for the mammogram, I realised how serious things must be when I took my clothes off in front of the technician. She looked horrified when she saw the breast ...

### Rahma, 40, Buckinghamshire

Rahma was given her diagnosis after hospital visiting hours, when she was alone, using terms that she didn't understand. The experience of her diagnosis was confusing and more distressing than it should have been.

I was told that it was Burkitt's Lymphoma on the evening of April 17. I wasn't happy that they told me after visiting hours, at around 9:30 at night, when I had nobody there with me. I had no family support. I actually had to ask them if Lymphoma was cancer, because they weren't saying it. I was upset and emotional and just in a daze with it. I think a part of my mind stopped me really taking it all in while I was just alone.

## Personalised care

Some people – particularly those with higher levels of socio-economic deprivation – may have different, more varied or even more severe needs. They may be diagnosed with later stage cancer [see the diagnosis sections in this report] or have more non-clinical needs [see the practical and social care, and the emotional and psychological, needs sections later in this report].

It's welcome, then, that NHS England have used their Long-Term Plan for England to reiterate a commitment to personalised care. But personalised care will not address inequalities by default. It's important we ensure everyone diagnosed with cancer has:

- High quality, supportive conversations with professionals that are trained and confident in discussing the clinical and non-clinical needs that can result after a cancer diagnosis.
- A Holistic Needs Assessment (HNA) in a format and setting that enables staff to capture all their relevant needs—including any needs associated with living on a low income or socio-economic deprivation (for example around housing, and finances).
- Personalised care and support plans that capture these diverse needs, including any non-clinical needs.
- Support with making decisions around any treatment, regardless of their health knowledge or health literacy, to access the treatment and care that will individually benefit them.
- Care navigation or links into wider health and care support, beyond their immediate need for treatment for cancer. This needs to take into account that not everyone will have the same capacity to self-manage – and some patients will need additional support and empowerment to manage their health and care needs.

Recent analysis of Cancer Patient Experience Surveys suggests the promise of personalised care and support isn't happening for everyone, at least not equally (Table 2 opposite).

### Positives and challenges

There are some positives. People from the most income deprived areas are more likely to receive care plans than the least deprived groups. This is testament to the work we know that many NHS services and trusts are driving forward at the frontline and in communities, based on patient experience scores.

However, there are still problems, with personalised cancer care staying out of reach for some. Access to the information and communication people need and rightly expect after a cancer diagnosis is harder for the most socio-economically deprived groups, and of a poorer standard. This is despite evidence that shows people in this group also typically have lower levels of health literacy.<sup>49, 50</sup>

Equally, the fact the most socio-economically deprived patients get the same access to care plans than the least deprived patients does not outweigh the fact that the total number who report receiving them is only 41%. This means that only a minority of patients who would most benefit from tailored support and help navigating the health and care system after a cancer diagnosis are receiving it. Programmes that use personalised care extensively, such as Macmillan's experience of the Improving Cancer Journey Programme in Glasgow, have shown excellent results for the most deprived people that use it (see 'Integrated Care' chapter).<sup>51</sup> As such, we must see progress towards full coverage of personalised cancer care, for those that need it.

Level of deprivation	Most deprived	Least deprived
Did you understand the explanation of what was wrong with you? (% who could completely understand it)	<b>72%</b>	<b>74%</b>
When you were told you had cancer, were you given written information about the type of cancer you had? (% who received written information, even if it was difficult to understand)	<b>72%</b>	<b>74%</b>
Were you involved as much as you wanted to be in decisions about your care and treatment? (% who felt involved as much as they wanted in decisions)	<b>77%</b>	<b>79%</b>
Did hospital staff give you information about support or self-help groups for people with cancer? (% offered information, or who stated they didn't need information)	<b>84%</b>	<b>87%</b>
After the operation, did a member of staff explain how it had gone in a way you could understand? (% who felt they completely understood the explanation)	<b>77%</b>	<b>80%</b>
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital? (% yes)	<b>94%</b>	<b>95%</b>
During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)? (% of those who needed support who received sufficient support)	<b>51%</b>	<b>56%</b>
Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)? (% of those who needed support who received sufficient support) (% of those who needed support who received sufficient support)	<b>43%</b>	<b>48%</b>
Have you been given a care plan? (% yes)	<b>41%</b>	<b>32%</b>

Table 2: Results from the National Cancer Patient Experience Survey (NCPES) 2017 in England. Scores provided for Indices of Multiple Deprivation for quintiles 1 (most deprived) and 5 (least deprived). Only significant differences shown.<sup>48</sup>

## Making personalised care effective care

Even with full uptake, it's important that personalised care translates into better care and support for everyone. In table 2, despite being the socio-economic group that receive the most care plans, people living in more deprived areas are still least likely to then go on and receive support from community and social services.

This may suggest that care plans alone do not lead to the levels of care essential for people with high levels of need. So it's vital we ensure early, supportive conversations lead to holistic assessments of health and care need; and this translates into fully personalised care, including support with navigation. While these interventions on personalised care need to be made available on a population-wide basis, implementing them requires specific effort and resource to deliver for excluded communities to ensure a positive overall impact on population health and a reduction in health inequality.

## A possible way forward

The Universal Model for Personalised Care in England outlines an approach that could prove useful. There is much to welcome in the commitment that the Ministry of Housing, Department for Work and Pensions and other partners across government will work alongside health and care to address the full range of non-clinical needs people face when living with long-term health conditions. Extra support for people with severe or complex needs to help them self-manage their health and care also looks likely to benefit the most socio-economically deprived patients. However, it's important we build on existing good practice. And it's critical we combine a model for universal personalised care with targeted work specifically aimed at health inequalities.



## Access to treatment

There is no good reason why treatment of cancer should vary according to someone's socio-economic status. Yet, in practice, it often does. People in England receive less surgical treatment in the most deprived areas (40%) than the least deprived areas (48%).<sup>52</sup> Differences in access to treatment have also been shown to explain international survival differences in some cancers,<sup>53, 54</sup> making variation in access to this treatment a potential explanation for survival inequality between people – and an important area to double down on inequalities.

Macmillan's partnership with the Information Services Division (ISD) in Scotland shows a similar trend. The analysis examined the 'excess mortality' risk (that is, any avoidable variation in deaths from cancer in a given group, compared to population mortality rates) of patients diagnosed between 2004 and 2008 over five years. Increased risk of 'excess mortality' for people in the most deprived areas, compared to the most affluent is set out in Table 3 below:

Unequal access to treatment – and particularly surgery – was a consistent factor which increased 'excess mortality' risk.<sup>55, 56</sup> This further demonstrates that variations in treatment can be a direct link to outcomes – a pattern likely to exist in a similar way in England.

As we look to make access to treatments more equal, it's vital we also ensure new cancer treatments do not make existing health inequalities worse. As inequalities already exist in access to treatment, (and some of these are avoidable) it's important

NHS services continue to monitor how making medical and scientific advances available to all contributes to improvements in population health. Making some new treatments widely available (for example genomics and molecular diagnostics), mustn't inadvertently lead to poorer access to others.

### Inequalities in clinical research

Macmillan's research shows that the most socio-economically deprived people receive just half the number of referrals to early-phase cancer clinical trials compared to the least deprived.<sup>57</sup> There are several reasons to prioritise more equal access to clinical trials. It ensures people have equal chance to access new treatments that may have clinical benefit; and improves data quality on how different treatments can benefit different patients. One possible solution is better training for staff building awareness of cancer research and referring the most deprived patients to clinical trials.

Prostate	<b>98% increased risk</b>
Breast cancer	<b>89% increased risk</b>
Head and neck cancer	<b>61% increased risk</b>
Colorectal patients	<b>45% increased risk</b>
Liver cancer	<b>28% increased risk</b>

Table 3: Increased risk of mortality faced by people from the most socio-economically deprived areas in Scotland

## The health and care workforce

As shown by Macmillan's recent report, *One Size Doesn't Fit All*,<sup>58</sup> the NHS is struggling to keep pace with the increasing and more complex needs of people with cancer.

We concluded the cancer workforce needed more professionals to manage the growing number of patients living with cancer and other long-term conditions. Our research also showed big differences in the ratio of clinical nurse specialist posts for each new cancer patient,<sup>59</sup> with proof that some specialist staff are having to fill gaps elsewhere in the NHS workforce.<sup>60</sup> We will clearly be unable to address the problems highlighted in this report without an adequately sized, skilled and sustainable workforce.

However, it's also important that the workforce has the right support and skills to specifically tackle inequalities in health. As we've already highlighted, providing targeted support through personalised cancer care is likely to be one of the best ways to tackle health inequalities – including those determined by social factors.

But targeted support relies on health and care professionals having high quality communication skills, plus the right behaviours, so they are able to embed shared decision making, personalised care and support planning in cancer care. This requires proper planning through workforce strategies. Both today's workforce and future professionals must receive the education and training they need to provide care that meets the increasingly diverse needs of England's growing cancer population.

### Gaps in professional support

Recent Cancer Patient Experience Survey (CPES) results (Table 4) suggest not all patients are receiving the professional support they want and need. In many cases, gaps in support are most acutely experienced by patients from the most income deprived areas.

Though there are one or two instances where experiences of professional support are better for those from more deprived areas, these results show a distinct pattern:

consistently lower quality communication between healthcare professionals and the most socio-economically deprived patients.

There are several substantial differences in self-reported patient experience linked to the level of deprivation. This highlights the need for thorough training for key health and care professionals – delivered either pre-registration, or post-registration through continuing professional development programmes. Advanced communications skills enable professionals, like clinical nurse specialists, to provide bespoke information and support which all people living with cancer need, no matter what level of health awareness they have.

'Downgrading' or 'down-banding' – the trend which points to deskilling as fewer specialist nurses are employed at higher bands – makes the situation worse. Only 71% of band 6 cancer specialist nurse roles have advanced communication skills compared to 89% of band 7 cancer specialist nurses.<sup>62</sup> So it's worrying to see there's been an increase in the proportion of cancer specialist nurses in the lower bands since 2014.

Workforce planning must consider how this trend affects the skills mix of teams, and professionals' ability to provide specialist support to the whole population of people living with cancer.

Level of Deprivation	Most deprived	Least Deprived
Were the results of the test explained in a way you could understand? (% yes, definitely)	<b>77%</b>	<b>81%</b>
Did you understand the explanation of what was wrong with you? (% yes, definitely)	<b>72%</b>	<b>74%</b>
When you were told you had cancer, were you given written information about the type of cancer you had? (% yes, definitely)	<b>72%</b>	<b>74%</b>
Were the possible side effects of treatment(s) explained in a way you could understand? (% yes, definitely)	<b>74%</b>	<b>73%</b>
Were you involved as much as you wanted to be in decisions about your care and treatment? (% yes, definitely)	<b>77%</b>	<b>79%</b>
When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand? (% most of the time)	<b>85%</b>	<b>89%</b>
After the operation, did a member of staff explain how it had gone in a way you could understand? (% yes)	<b>77%</b>	<b>80%</b>
Did groups of doctors and nurses talk in front of you as if you weren't there? (% no)	<b>78%</b>	<b>85%</b>
While you were in hospital did the doctors and nurses ask you what name you prefer to be called by? (% yes)	<b>70%</b>	<b>68%</b>
During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears? (% who needed to, who had sufficient discussion)	<b>55%</b>	<b>52%</b>
Overall, did you feel you were treated with respect and dignity while you were in the hospital? (% yes)	<b>89%</b>	<b>90%</b>
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital? (% yes)	<b>94%</b>	<b>95%</b>

Table 4: Results from the National Cancer Patient Experience Survey (NCPES) 2017 in England. Scores provided for Indices of Multiple Deprivation for quintiles 1 (most deprived) and 5 (least deprived). Only significant differences shown.<sup>61</sup>

## Emotional and psychological needs

Almost half of people living with cancer have unmet emotional needs (45%).<sup>63</sup> Too often, emotional and psychological needs go unrecognised or unsupported. For people who experience these needs more often, or more severely, a lack of support will be an even greater problem.

In new Macmillan research, released for the first time in this report, **a third (33%) of all people living with cancer in the UK expressed cancer-related concerns around loneliness and isolation. However, this proportion rose to nearly a half (47%) among those with a household income of less than £10,000/year.**<sup>64</sup>

### Mental health inequalities

Macmillan has contributed to a study published in the British Medical Journal that further shows that depression affects 20% of cancer patients, compared to 5% of the general population. A 2014 study in the Lancet similarly concluded:

“Major depression is common in patients attending cancer clinics and most goes untreated. A pressing need exists to improve the management of major depression for patients attending specialist cancer services”.<sup>65</sup>

Socio-economic status was a significant risk factor.<sup>66</sup>

Again, this was seen in new Macmillan analysis of the needs of people living with cancer. **Those on lower incomes were more likely to express a need for additional support around issues such as sadness and depression (mentioned by 31% of those with a household income of less than £10k, compared to 22% of the cancer population overall).**<sup>67</sup> Indeed, **people with cancer with a household income of less than £10k are almost twice as likely to need this type of support compared with those with a household income of more than £50k (17%).**

Similarly, over a quarter (29%) of those with a household income of less than £10k indicate that they would like more support to tackle loss of confidence (mentioned by 29%, compared to 17% overall) – making them twice as likely to need this type of support than those with a household income of more than £50k (13%).

### Closing the support gap

NHS England accepts that mental and physical health are interwoven – acknowledging in their long-term plan that people with severe mental illnesses tend to die 15-20 years earlier than those without severe ill mental health.<sup>68</sup> Our new analysis suggests that health policy makers must consider the emotional and mental health needs of people diagnosed with a long-term condition, such as cancer, in their approach to health inequalities.

Simply put, deprived or not, people living with cancer are not getting all the emotional or psychological support they need – with the most deprived people more likely to have these needs unmet. Ensuring cancer services are set up to recognise emotional health needs, through supportive conversations for all and holistic needs assessments, are essential interventions.

What’s more, recognising the scale of unmet needs and the extent of support needed by the most deprived groups is also vital. Possible solutions like more access to talking therapies and other psychological interventions also need to be explored.



# Impacted by health inequality

## Kate, 39, Northumberland

Kate is a mother-of-one and has income worries. Despite having a history of depression, Kate did not receive any emotional support after she was diagnosed with cancer. Her mental health problems compounded an already difficult experience of living with cancer and she felt she could have benefitted from support navigating the care system.

I was out of breath all the time, sometimes I would just lie on the sofa and do nothing. I couldn't talk to anyone as my husband's mum is very ill and with the money problems we were having, he just had to work all the time, so couldn't be there. I found it really difficult to cope with my cancer diagnosis, as I already have a history of depression. Other than having a health visitor who saw me once a month, I had no support. I was never signposted to anywhere where I could get help.

## Sandra, 43, Tyne and Wear

Sandra has been unable to work since her cancer diagnosis. Her benefits are less than her outgoing expenses, especially due to travel and paying for hospital parking. She gives some insight into the barriers people can face during their cancer treatment including practical barriers, which we discuss later in this report.

The care that I was getting was good, but I was very emotional when I was diagnosed with breast cancer. Right now, I am following the treatment, which is not yet finished. I have had no difficulty in being prescribed drugs, which make me more hungry, and also tired. My finances are very affected because I can't work but I have to spend more money because I have to go to the hospital most of the time for appointments etc ... I have to pay hospital car parking all the time and also for fuel, but am still going to my treatment.

## Donna, 61, London

After losing her income, Donna had to sell her car – isolating herself – and could barely afford energy bills and food. She had to rely on Macmillan grants to be able to simply cook and keep her heating on and fridge running.

I sold my car to make ends meet. This depressed me more than everything else as I wasn't strong enough to carry shopping and I was not on the internet to organise home shopping. I felt isolated as my social life had ended as I could not afford to go out with my old work colleagues like I used to. I lost contact with the world I knew ... If it wasn't for Macmillan, I would not be able to cook a full meal, or keep my food chilled, or relax a bit more in the cold winter months.

## Practical and social care needs

A clearer picture is emerging of how people's practical needs create inequality after a cancer diagnosis. Around two in three people living with cancer (64%) have practical and social care support needs. Almost a third of people living with cancer (31%) do not get enough support and one in five (22%) experience a negative impact on their life as a result. These include – being housebound, being unable to wash and unnecessary hospital admissions.<sup>69</sup>

New research conducted by Macmillan indicates that people living with cancer on low incomes in the UK are more likely to express a need for support with practical tasks at home than those on higher incomes. Those with a household income of less than £10k are twice as likely to say that they would like more support with practical tasks than those with an income of more than £50k (38% and 19% respectively).

**A starker contrast emerges around practical tasks outside the home – 34% of those with an income of less than £10k say that they would like more support in this area, compared to 13% of those with an income of over £50k.**

Many people with these needs (42%) are eligible for statutory support but are not receiving it. In fact four in ten people living with cancer have levels of practical or social care need that would make them eligible for local authority support. This rises to around eight in ten at the end of life (84%).<sup>70</sup> Other research has made clear that socioeconomic background is a key determinant of the gap between people's social care needs and the provision they receive.

**The King's Fund have shown that this is an inequality issue. They estimate a 23% gap between social care need and provision in the lowest income group, compared to an 8% gap in the highest income group.<sup>71</sup>**

### Cuts and inequalities

It's difficult to talk about this issue without bringing up the impact of local authority funding cuts. Central government funding for local authorities in England fell by nearly 50% between 2010/11 and 2017/18. The funding gap in adult social care is estimated

to be £1.5 billion pounds, which could rise to £6 billion pounds by 2030.<sup>72</sup>

What's more, there are concerns that a new fairer funding formula in local government may take money away from more deprived areas<sup>73</sup>. This would undercut commitments by NHS England to redistribute funds to deprived areas through the Health Inequalities Funding Adjustment [see funding for inequality chapter]. It would be hard for this not to impact people's health – indeed, a 2018 survey of adult services directors showed a concern that services are just about managing. While 34% of adult services directors were fully confident in meeting their statutory duties in 2018/19 (59% partially confident), only 10% were fully confident for 2019/20 (66% partially confident) and 0% for 2020/21 (34% partially confident).<sup>74</sup> This is likely to increase the risk that people with social care needs do not get the support they need.

The 2019 Comprehensive Spending Review has the means to address barriers to social care and provide investment that would help tackle inequality faced by people living with cancer in the most deprived areas. The Local Government Association has shown that more sustainable levels of funding would lead to better leadership at a local level and efficiency savings for the taxpayer.<sup>75</sup>

The rest of the health sector could also have a role to play in meeting practical care needs for people living with cancer in the future, including through community settings. The health sector should continue to link people with cancer to practical and community support that supports their overall wellbeing. This could provide a joint-commissioning opportunity to deliver better integration between health and social care providers.

## Palliative and end of life care

Macmillan has published several reports that point to unjust variation in end of life care for people with cancer, including *The Final Injustice* and *Missed Opportunities*. In the first we showed that people from the most deprived groups were more likely to die in a setting not of their choice, were more likely to experience a lower quality of life and have more emergency admissions in their last year of life.<sup>76</sup>

In *Missed Opportunities*, we explored some of the barriers that prevent people from having better quality experiences at the end of their lives, concluding that: “At Macmillan, we know that too many people’s preferences at the end of life are not being met. In some cases, people might not be aware that they have a choice about their care in the final days. [Advanced Care Planning] conversations ensure people are given the chance to record their hopes, wishes and fears in the future. However, the evidence presented in this report has revealed that there are many barriers to enabling these vital conversations”.<sup>77</sup>

Beyond the unacceptable impact on individual patients, emergency admissions in the last year of life currently cost the NHS around £2.5 billion/year – some of which could be avoided by more equitable provision of advanced care planning.<sup>78</sup> Indeed, emergency admissions have been one of the fastest growing sources of health expenditure since 2011, suggesting there is scope to combine action on inequality with efficiency savings.<sup>79</sup>

Personalised care at the end of life – using tools such as (but not limited to) Advance Care Plans in England – provides an excellent way to ensure that people’s choices and preferences are respected, and that they experience fewer emergency admissions. Plus there are other interventions that could help us ensure the most deprived population has the best chance of good care and a better quality experience at end of life. One of these is better health literacy, as Lewis’ systematic review concludes: “Mistrust in palliative care for the socioeconomically deprived was often paired in the literature with concerns around communication ... Communication practices in palliative care

were seen to facilitate further barriers to access for the poor. Limitations for socioeconomically disadvantaged groups to engage in communication required for open discussion around diagnosis and prognosis [and] ... Misinformation and misconceptions about end-of-life care, based on unaddressed poor health literacy, represent barriers to access”.<sup>80,81</sup>

There could also be greater recognition of the role that support networks play in enabling good quality End of Life Care. A 2014 qualitative study (semi-structured interviews) showed that: “Networks and relations of support are essential for ensuring quality end of life care is achieved. Lower socioeconomic groups are at a distinct disadvantage where these networks and relations are limited as they lack the resources necessary to augment these gaps. Understanding the nature of assets and limitations in networks and relations of support is necessary to inform interventions ...”.<sup>82</sup>

Finally, it’s worth noting that the Care Quality Commission (CQC) has previously highlighted a lack of targeted commissioning of palliative and end of life services to meet the needs of demographic groups known to experience inequalities. They go as far as to say: “Some commissioners and providers might not be fulfilling their duties under the Equality Act 2010 as all public bodies have a legal duty to consider the needs of a range of equality groups when carrying out their day-to-day work”.

In the same analysis, CQC highlight a lack of early conversations about the end of life. Training staff to deliver high quality, inclusive and personalised palliative and end of life care could help to address this.<sup>83</sup>

## Integrating across the community

Better integration has often been talked about as a route to tackling health inequalities. However, we must be careful not to mistake the potential of a system to alleviate inequalities with a guarantee that it will. The success of integration will be realised in both the range and strength of partnerships across the voluntary, health and care sectors and how care is transformed across care boundaries. It will also be about the extent to which integration is experienced at an individual level, as Macmillan argued in the report *Thinking it Through*.<sup>84</sup>

As local areas move towards Integrated Care Systems in England, this means people working towards integration should consider, among other things:

1. Not every community has equal assets. For example, some areas have community infrastructure (eg transport) which better facilitates people with cancer to access healthcare and meet their full range of care needs. Rural or remote areas often have less infrastructure and so less capacity to meet their population's range of health and care needs. A lack of infrastructure is likely to impact people on lower incomes the most, as their financial means are likely to limit the transport options available to them. Integrated care therefore needs to be designed to help the most deprived groups surmount the barriers that can make travel to health and care facilities more difficult.
2. As we see a continued shift in care delivery, away from hospital settings to more community-based forms of care, it is important integrated care for people with cancer includes the right range of partners. For socio-economically deprived people, this could include housing, financial advice and welfare support, employers and transport providers. The partnerships in any local area should consider the unmet needs of that population, and particularly the unmet needs of the most excluded groups in that population. There is an immediate opportunity to drive greater partnership working to tackle health inequalities in England, given the commitment for all areas to transition to Integrated Care Systems by 2021.

Macmillan is using integration to tackle inequalities through the Improving the Cancer Journey (ICJ) Programme in Glasgow. This uses a multi-partnership model to bring together existing providers from the health and wider welfare sectors – including employment, welfare and housing support. From the start date (2014) until the end of August 2017, ICJ had seen 2,413 people affected by health inequalities:

- The majority were from the most deprived areas of Glasgow. Over 6 in 10 came from the lowest quintile areas and 77% came from the most deprived two quintiles.
- Over half of the people accessing this service had at least one other multiple condition.
- 13,168 needs were identified in total. The top three concerns were: money and housing, feeling fatigue/tired/exhausted and getting around.
- People's concern levels were substantially reduced on return visits, with average scores reducing from 7.15 to 3.82\*. Recipients said they valued the consistency of having one person to help them with everything, and of having a link worker to help navigate the system.<sup>85</sup>

It shows the potential benefit of taking a population approach to the health of people living with long-term conditions. Improving the Cancer Journey is continuing in Glasgow and is now being piloted more widely in Scotland with similar approaches being introduced in Powys, Wales.

\*A self-reported score of concern between 1 and 10.

## Funding for inequality

Finally, with the costs of inequality clear, it's equally clear that making progress on health inequalities needs upfront investment. Evidence suggests that allocating funding to specifically tackle inequalities in health is both efficient and impactful.<sup>86, 87, 88</sup>

There is also much promise in the approach to the inequalities funding adjustment taken by the NHS Long-Term Plan, which:

- allocates a funding adjustment based on level of inequality in a local population – to Clinical Commissioning Groups (CCGs) (10%) and primary care (15%)
- asks commissioners to then outline how this will be used to alleviate inequalities in five-year and ten-year plans – in the context of Sustainability and Transformation Planning and the transition to Integrated Care Systems by 2021.

Local plans on inequalities give commissioners an opportunity to continue work reducing health inequality. However –

it's important that NHS England and their resource allocation advisors – the Advisory Committee on Resource Allocations (ACRA) – consider whether prioritisation of inequalities means that a funding adjustment for CCGs should return to the 15% level of 2012, in line with best evidence.<sup>89, 90, 91, 92</sup>

But it's not just health funding that's important. Public health and local authority funding is also critical if people with long-term conditions are to receive all the services and support they need. This is particularly true in cancer care, where public health and social care investment is necessary to achieve genuinely integrated care. More sustainable funding could be achieved through the Comprehensive Spending Review later in 2019.



# Impacted by health inequality

## Renee, 47, Wiltshire

Despite his care being free, Renee found that costs associated with her brother's end of life care were hard to deal with, meaning the family had to use all of their savings and rely on a grant from Macmillan. This came as a shock to Renee, who never knew they would have incur so much out of pocket expenditure outside of her brother's immediate care needs.

After his terminal diagnosis ... [he] was able to get support from nPower for the energy bills, but the family still needed a Macmillan grant to help get by. We never thought we had to pay for his care, and even though the social care was free there were still a lot of costs associated with caring for him, which meant that his partner spent all of her own savings during this time.

## James, 63, London

James had just lost his job before his diagnosis, and his finances were so stretched that he couldn't even afford to travel to and from hospital or afford basic necessities. He had multiple long-term conditions, was unemployed, and felt his experience was more emotionally difficult than it needed to be.

I was having a terrible time. I had just been suspended from my job, without pay, before the cancer diagnosis. So I was very strapped for cash ... I couldn't even afford the bus fares to take me to the hospital for my treatments ... Macmillan came to my aid.

## Laura, 53, London

When her friend was diagnosed with uterine cancer, Laura stepped in to help, as her friend lived alone and had nobody else to care for her. Her friend was vulnerable, experiencing mental health problems that caused alienation between her and healthcare staff. Despite the fact that she lived alone, her healthcare team missed opportunities to make her experience better – such as sending her home from hospital late at night, when she couldn't make it up the stairs to her bedroom. Laura feels that better communication and involvement on the part of the healthcare system would have improved her friend's experience at the end of her life.

My friend had uterine cancer. She lived by herself, so I knew that she would need some extra help. She went into the chemotherapy and was doing quite well for a while, but then it all started to go downhill. As she entered the end of her life, I can't tell you what she went through. It was just horrible. She was in and out of hospital. On one occasion she was sent home from hospital, alone, at 11pm. She had to be helped by two paramedics back into the house because she was so ill and exhausted that she couldn't move. She had a bed downstairs, but they left her in the chair. She ended up spending the night just sat in that chair by herself because she wasn't able to get herself into bed. In the end she couldn't get in the bath or shower, but she would wash at home using special wipes. She wouldn't let me bathe her. She was too proud for that sort of thing ... She was depressed and distressed and she needed things explained to her.



Oh, that you would  
Miss me and enlarge  
my territory! Let your  
hand be with me, and  
so that I will be free  
from pain.  
1 Chronicles 4:10

MM



Shopping List  
Pay energy  
Bill ☺



# OPPORTUNITIES FOR ACTION IN 2019 AND BEYOND

- 1. Local inequality targets for the next five and ten years:** Macmillan recognises the excellent local work often done on the health inequalities agenda. Local plans will continue to be important, and the approach of linking future funding flows to measurable objectives looks promising. Local objectives should tackle known inequalities across the cancer pathway – as outlined throughout this report.
- 2. The shift towards Integrated Care Systems by 2021:** Macmillan’s experience with Improving the Cancer Journey (ICJ) has shown that integration can provide long-term benefit in addressing health inequalities. This will not, however, happen by default. Implementation of integrated care needs to consider who will be the right partners to meet the needs of the most vulnerable or deprived populations. And how the right navigation can be provided across health and care, as we move to integration as ‘business as usual’ – whether that’s through Integrated Care Systems (as NHS England is moving towards by 2021), or other models.
- 3. New inequality targets for national programmes following the NHS Long-Term Plan in England:** Major programmes have been asked to develop targets to reduce inequalities. This is an opportunity for engagement with under-served groups and the first opportunity to set out a more compelling vision on tackling health inequalities for the 2020s. We hope to see a first indication of what this will look like in NHS England’s National Implementation Framework for its long-term plan.



- 4. Changes to the inequalities adjustment in the health funding formula in England:** The Advisory Committee for Resource Allocation (ACRA) will be commissioned to review the funding formula that allocates health funding to Clinical Commissioning Groups. This should provide different options for funding adjustments for NHS England to consider - and demonstrate - what targeted action on health inequalities these funding adjustments should lead to. ACRA have previously stated that funding adjustments are measures of how highly an issue is prioritised, implying that an increase to match NHS England reprioritisation of health inequalities would be reasonable in 2019.
- 5. The Comprehensive Spending Review:** This can provide funding for social care, public health and local authorities, plus workforce education and training – to complement the extra funding given to health organisations to tackle inequality. This would enable key partners within the health economy to tackle inequalities through, for example, delivery of more personalised, integrated care.
- 6. 2020 marks the ten-year anniversary of the flagship Marmot Review on health inequalities, as well as what has been called the ‘English Inequality Strategy’ [1997-2010].<sup>93, 94</sup>** The anniversary could be marked by a more compelling, ambitious vision of how we will tackle inequalities at a national level, through cross-government action. This would best be achieved through a green paper, forward view or inequality strategy.

## Conclusion

Now there is a Long-Term Plan for the NHS in England we need sustained action and momentum to tackle health inequalities. Through local and national action, we need to all address a wider range of inequalities across the care pathway, not just for preventing disease, but also to benefit people living with cancer and other long-term conditions after the point of diagnosis. This is critical to ensure that both good outcomes and the opportunity to have the highest possible quality of life, are not unjustly defined by who you are or where you come from.

We believe the following three principles, currently not embedded in national policy, represent a compelling plan for reducing health inequalities in the 2020s:

- 1. A clear vision for tackling inequalities both locally and nationally, to ensure that measurable plans and objectives push in the same direction.** This should look to facilitate a whole-systems approach to tackling inequalities– with action across public services. This would mean the inequalities people face before and after a cancer diagnosis can be systematically addressed – and not just in a ‘health service silo’.
- 2. A clear account of the exact resources, evidence and support local providers will need from national governments to deliver on inequalities** – and a plan to provide the full support they need.
- 3. A commitment to targeted action where inequalities are most in need of attention – that is, to ensure that new health policies and interventions consider from the outset how they will benefit the most commonly excluded groups.** Here new services and interventions should be evaluated in terms of how they improve outcomes for groups experiencing the worst outcomes today.

This requires us not just to take the opportunities available to us now, but to also create the momentum, resources and opportunities to tackle this enduring problem. Our goal is to see inequalities dramatically reduced in cancer, and across health and care more widely, over the coming ten years.

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